

Kentucky CSHCN Maternal Child & Health Services Block Grant 2016 Application/2014 Annual Report/Five-Year Needs Assessment Summary

Each year, states are required to submit an Application and Annual Report for Federal funds for their Maternal and Child Health Services Title V Block Grants. While the Kentucky Department for Public Health (DPH) is the Kentucky grantee, federal guidance requires that at least 30% of Title V funding be allocated for services for Children and Youth with Special Health Care Needs (CYSHCN). Services for CYSHCN are administered in Kentucky by the Commission for Children with Special Health Care Needs (CCSHCN) and include providing and promoting family-centered, community-based, coordinated care (including care coordination services) for CYSHCN and facilitating the development of community-based systems of services for CYSHCN and their families.

This document summarizes the draft application & report of the portion of the Application and Annual Report pertaining to CYSHCN, as well as the Five-Year Needs Assessment Summary.

Comments	CCSHCN wants to hear your input! If you have any comments about the content of this summary document, or would like more information about the Maternal Child & Health Services Title V Block Grant program in Kentucky as it pertains to CYSHCN, please contact Mike Weinrauch via e-mail: mike.weinrauch@ky.gov or via phone: (800) 232-1160, ext. 2026. Anonymous comments may be submitted via a survey link on our website, or by visiting: http://www.surveymonkey.com/r/2016MCH
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Needs Assessment Summary	<ul style="list-style-type: none"> ▪ Process - activities included: <ul style="list-style-type: none"> ▪ Data analysis of most recent National Survey of Children with Special Health Care Needs (NS-CSHCN) and most recent National Survey of Children's Health (NSCH) ▪ CYSHCN prevalence estimates for select chronic conditions, based on Kentucky Department of Education school health data (regional variation data currently under examination) ▪ Distribution, collection and analysis of MCH and CCSHCN patient surveys ▪ Statewide MCH (health department) and CCSHCN professional staff focus groups ▪ MCH Stakeholder Meeting ▪ Findings: CYSHCN Population Needs <ul style="list-style-type: none"> ▪ CCSHCN reported population improvement in six of eight performance measures (six national, two state-level) examined between the period of 2009 and 2014. The number of infants screened for hearing before hospital discharge revealed a slight decline from 99.9% within this timeframe, due in part to better tracking and an increase in home births. Another measure – tracking childhood BMI – rose slightly in 2013 and 2014, though no discernible trend is evident over the five year period. ▪ The Graduate Student in Epidemiology Program (GSEP) analysis of 2011/2012 NSCH and 2009/10 NS-CSHCN data compared Kentucky outcomes to HRSA Region IV and national results. Overall, Kentucky fared well as compared to HRSA Region IV and the nation. Two measures were targeted for improvement: <ul style="list-style-type: none"> ▪ Access to community-based services; and ▪ Transition services ▪ When condition prevalence was examined for these same areas, Kentucky had more children living with: <ul style="list-style-type: none"> ▪ Asthma; ▪ Arthritis; ▪ ADD or ADHD; ▪ Behavioral or conduct problems; ▪ Epilepsy/seizure disorders; ▪ Heart problems; and ▪ Cerebral Palsy.
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- Kentucky fared better than either Region IV or the nation in autism prevalence and blood problems.
- When asked about needs for CYSHCN, Kentucky's MCH **patient survey** respondents said that their greatest concerns were:
 1. Making sure families have the ability to receive services;
 2. Ability to find insurance to pay for care;
 3. Availability of developmental, social, and emotional screening services;
 4. Training and support for children with behavioral issues; and
 5. Finding doctors who can provide care
- However, when this same category was examined using only data from **families of CYSHCN enrolled in CSHCN clinical programs**, priorities varied slightly.
 - The need to find insurance moved off the list completely and was replaced by concerns about finding doctors to provide care as the second priority issue.
 - Training and support for children with behavioral issues moved to the third priority and the need for early identification of special health care needs was added to the list.
- When patient survey responses were examined by Kentucky region, some interesting and statistically significant variations occurred:
 - Finding doctors who can provide care was of greater concern in Western Kentucky than in Eastern Kentucky, though the latter is known for its provider shortages;
 - Finding insurance to pay for care was more of an issue in Central Kentucky;
 - Nearly one quarter of respondents from Eastern Kentucky said that early identification of CYSHCN was a high priority need in their region; and
 - The need for transition services was thought to be greater in Eastern Kentucky
- **Focus groups** discussed issues pertaining to CYSHCN and their families. Access to resources and services was the primary topic of discussion but the impact of substance abuse on families and communities, as well as the increased risk for child abuse, were also highlighted.
 - Specialized providers are not available in many rural areas of the Commonwealth. The lack of pediatric dentists and pediatric mental health providers was noted as were barriers families faced as they traveled long distances for needed specialty care. Medicaid offered help for some, providing vouchers for transportation that was arranged well in advance. However, to qualify for this benefit, families had to prove that they had no other means of transportation available. If they were merely unable to pay for gas that month or owned an automobile that was not currently safe to drive, they did not qualify for support. Unless their car was certificated as non-functional by a licensed automobile mechanic, they were deemed ineligible. The cost for such a certification started at \$75.00 and could be well over \$100.00 depending upon the community.
 - A few rural communities sponsored a shared ride option for families who were traveling on the same day to the same urban center for their child's appointment. This mode of travel was certainly helpful but encompassed the entire day as families were dropped at their respective appointments across the city. Until their scheduled pick-up time, they remained at the clinic location with a special needs child who may be hungry, tired, and uncomfortable. These trips often ended late in the day when the van returned to their community in the early evening.
 - Public Health professionals reported that families of special needs children and youth often struggle to navigate existing systems of care. Sometimes

	<p>needed services are available, just unknown to caregivers. Parents may be overwhelmed by their responsibilities and the need for respite was frequently mentioned by focus group members. Also acknowledged was an increased risk of depression for families with few treatment options available to them; particularly in rural regions of the state.</p> <ul style="list-style-type: none"> Finally, participants talked about the current epidemic of substance abuse and long-term implications for child development and wellbeing. Some children seen at CSHCN clinics may have developmental delays influenced by prenatal exposure to drugs. While long-term implications of early drug exposure are not yet fully understood, medically fragile children are known to be at higher risk for abuse and neglect. This fact emphasizes the need for continued support for families across the Commonwealth. The MCH stakeholder meeting included two tables devoted to CYSHCN issues. Selected for in-depth exploration and discussion were access to care, provider capacity and supports/resources for families. <ul style="list-style-type: none"> Gaps identified by stakeholders for access to care included provider shortages, transportation barriers and complexity of system navigation for families. Too few providers accept Medicaid in Kentucky, so enrollment does not equate with access to care. Possible solutions include the education of medical societies regarding barriers for CYSHCN and the creation of a CYSHCN resource hotline (for providers and families), expanded transportation opportunities for Medicaid enrollees and disability providers, increased use of telemedicine, and incentives for providers to serve in rural areas of the state. Stakeholders said that provider capacity was the next priority issue with a lack of specialists, too few multidisciplinary clinics, and reimbursement issues of primary concern. Limits on provider reimbursement at multidisciplinary clinics and for telehealth services exist. Ideas included collaborations with residency programs and communities to provide loan repayment support for young physicians as well as the increased use of physician extenders (such as nurse practitioners and physician assistants). To improve provider reimbursement, negotiations with managed care organizations (MCOs) for bundled payments for multidisciplinary clinics and special rates for CYSHCN were suggested. The final area was the need for support and resources for families of CYSHCN. Stakeholders acknowledged that too often families did not know what services were available in their communities and that many lived in resource-poor regions of the state. Solutions included blended funding, expanded outreach and marketing, and centralized resources to help families navigate services.
<p>State Selected Priorities</p>	<p>In selecting priority needs, CSHCN's leadership team attempted to include as many expressed priorities as possible, taking into special consideration alignment with MCH's six core outcomes for an integrated system of care for CYSHCN. In addition to perceived and documented needs identified by stakeholders and observed trends in both national and state-generated data, the number affected by an issue, the issue's impact on families, and the extent of agency capacity for systems improvement were considered in selection.</p> <ul style="list-style-type: none"> Three (3) interrelated priorities were merged to form a selected priority of easy access to care and services – defined in this context as including <ol style="list-style-type: none"> (1) Access to medical and specialty care, (2) Assuring the availability of provider networks to reach CYSHCN; and (3) Developing and promoting an easy to access system of supports and resources for CYSHCN and their families. This priority is inclusive of elements from CYSHCN outcome #5 for an integrated system of care – and was targeted for improvement in a study of NS-SHCN results.

	<ul style="list-style-type: none"> ▪ The improvement of transitions services was the other core outcome (#6), which, despite being a priority in the most recent Needs Assessment cycle, showed a lack of statistical progress as measured in the National Survey of Children with Special Health Care Needs (NS-CSHCN) and in fact regressed below both the regional and national averages. Due to the large number of CYSHCN affected (all), the effect on families (major), and the ability for the agency to undertake efforts to improve, transitions was selected as a focus. ▪ Along with DPH, CCSHCN is poised to address the cross-cutting issue of adequate insurance to pay for needed services as a third priority, given consistent family and consumer survey results throughout all areas of the state. ▪ The final CYSHCN priority is the improvement of data capacity was chosen as a result of the process itself. Despite an interest, the CYSHCN agency has not historically had the technical expertise necessary to analyze and incorporate non-clinical data. Of particular interest is bridging the gap between internal data regarding direct service enrollees and national data regarding all federally-defined and self-reported CYSHCN in Kentucky, as well as studying available data regarding provider network adequacy in geographic areas of the state.
<p>Linkage of Priorities with Performance Measures</p>	<ul style="list-style-type: none"> ▪ National Performance Measures (NPMs) are measurements of results or achievements on specific outcomes. Progress or lack of progress will be measured through the National Survey of Children's Health. Over the next year, several Evidence-Based and/or Evidence-Informed Measures will be developed to assist CCSHCN in achieving success in each of these areas. <ul style="list-style-type: none"> ▪ NEW NPM #12: Percent of adolescents with and without special health care needs who received services necessary to make transitions to adult health care ▪ NEW NPM #15: Percent of children 0 through 17 years who are adequately insured ▪ State Performance Measures (SPMs) are additional measures selected by Kentucky based on identified priorities and our own unique needs. Progress or lack of progress will be measured through an annual scoring of Kentucky's specific implementation plans. <ul style="list-style-type: none"> ▪ NEW SPM #X: Degree to which CCSHCN's plan to increase easy access to services and resource is implemented ▪ NEW SPM #Y: Degree to which CCSHCN's plan to increase data capacity is implemented
<p>Report on Most Recent National Performance Measures and State Performance Measures</p>	<p>For the past several years, CCSHCN has reported progress on 6 NPMs common to all states receiving MCH funding (and representing the elements of a well-functioning system for CYSHCN), as well as 2 SPMs (chosen by Kentucky as per the 2010 Needs Assessment). Each performance measure has a numeric indicator quantifying progress. This data has historically been measured in Kentucky through a combination of internal service data from the patient information system, and feedback received from CCSHCN enrollees via clinic comment cards. The measures are as follows:</p> <ul style="list-style-type: none"> ▪ NPM 2: The % of CSHCN age 0-18 years whose families partner in decision making at all levels and are satisfied with the services they receive ▪ NPM 3: The % of CSHCN age 0-18 years who receive coordinated, ongoing, comprehensive care within a medical home ▪ NPM 4: The % of CSHCN age 0-18 years whose families have adequate private and/or public insurance to pay for the services they need

- NPM 5: The % of CSHCN age 0-18 years whose families report that community-based service systems are organized so they can use them easily
- NPM 6: The % of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including health care, work, and independence
- NPM 12: The % of newborns who have been screened for hearing before hospital discharge
- SPM 7: Decreased % of children, ages 0-18, receiving CCSHCN services, with a Body Mass Index (BMI) at or above the 85th percentile
- SPM 8: Degree to which CCSHCN transition action plan is successfully completed and implemented

Following is bullet-point summary of the accomplishments and activities toward the CYSHCN health domain.

Annual Report (FY 2014)

- NPM 2 – Satisfaction & Partnership: 97.9%
 - 2100 clinic comment cards received during the reporting period
 - Nurse care coordination and multi-professional team approach continues
 - Nurse care coordinator now present at muscular dystrophy clinic in Louisville
 - Family to Family Health Information Centers (F2F) assisted nearly 2000 individuals
 - CCSHCN social work staff and F2F staff/support parents served as “kynectors” – part of a network of individuals trained to provide information and assistance with enrollment in the state’s health benefits exchange
 - F2F participation in Kentucky Infants Sound Start program to encourage newborn hearing rescreening follow up
 - Family participation through Parent Advisory Council and Youth Advisory Council avenues, as well as Strategic Planning retreat
 - Peer mentoring program through D70 grant
 - Parent participation in AMCHP Action Learning Collaborative – Standards
- NPM 3 – Medical Home: 96.0%
 - Transition out of gap-filling direct services in Lexington area; partner with local accredited medical home provider to ensure enhanced services, including behavioral health and pharmacy, are available for foster children and others needing services
- NPM 4 – Insurance: 96.8%
 - 27 agency-affiliated kynectors assisted approximately 3000 people during reporting period (participation began 10/13), and started over 500 applications during that time
 - PSI premium assistance program continued for Hemophilia and CF populations
 - Avesis (MCO dental administrator) special rate negotiated for Cleft Lip & Palate patients in need of complex and phased orthodontia treatment – attracted more providers and resulted in increased access to care
 - Prior authorization requirements for hearing aids and therapy services through one MCO have been reduced
 - Current Medicaid cost settlement for care coordination services
- NPM 5 – Community Based Services: 96.2%
 - Care coordination in and outside of specialty medical clinics

- F2F and social work system navigation and resource-brokering assistance
- Provision of gap-filling direct services – where waitlists exist, services are not otherwise available, or need for multi-disciplinary clinics exists
- Autism services
 - Pilot for ongoing medical care and diagnosis has begun in 4 offices
 - Convened Autism Advisory Council
 - Partnership with Kentucky Autism Training Center to develop training
 - Modification of offices to accommodate needs of patients
- Telehealth partnership – this option has been in all offices where there is a significant proximity to provider problem, neurology has been discipline of pilot
- NPM 6 – Transitions: 68.8%
 - One on one discussions with families enrolled in CCSHCN programs – based on transition checklist which documents what skills have been accomplished, are in progress or part of future expectations
 - Morehead pilot activities part of process statewide – outreach expectation to assist youths with handoff to adult care, knowledge, and preparation assurance – portable medical summary in use
 - CCSHCN is still actively involved in the Kentucky Interagency Transition Council for Persons with Disabilities and the 9 Regional Interagency Transition Teams (“RITTs”) across the state
 - Staff and F2F support parent participation in fairs, conferences, school events and shared information with families and professionals
 - Youth forum bringing together young adults (21-35) to identify barriers and opportunities for successful transition
 - Partnership with UK Human Development Institute to train and match mentors and mentees (16-20)
- NPM 12 – Early hearing screening: Data TBA (last year: 98.5%)
 - Hospital scorecards & proactive assurance of services, decreasing lost to follow up
 - Information system collects all newborn data and tracks progress through screening, diagnosis, and intervention
 - 11 of 12 offices provide ABRs
 - Hosted national EHDI conference and sponsored educational session
- SPM 7 – Healthy weight: 36.5%
 - Ongoing participation in 5-2-1-0 initiative for CCSHCN enrollees
 - Training by dietitians on accuracy of height and weight measurements, review of BMI status data
 - Partnership for a Fit Kentucky is a collaboration among network partners, where best practices are shared; local council involvement
- SPM 8 – Transitions Action Plan: 92.3%
 - See NPM #6
 - Progress made with regard to social media presence and assistance with transition to adult health care providers

Application Year (FY 2016)

- NPM 2 – Satisfaction & Partnership:
 - Physician survey developed to explore provider satisfaction and aimed to engage doctors as well as families
 - GSEP project to re-engineer data collection system to include not only CCSHCN enrollees, but non-enrolled CYSHCN, to capture additional dimensions of outcomes and process, and to conform to and supplement national data sources
 - Transitions administrator to follow up with families of aged-out

- CYSHCN to assist with overcoming barriers, conducting QA regarding transitions efforts and gauge how much families are understanding
- F2F to train support parents who will partner with FQHC and Spanish-speaking practice to provide parent care coordination support in-office
- Family presentation to branch managers and development of family-based proposals/wish list for executive team
- F2F to train Spanish support group facilitators

▪ NPM 3 – Medical Home: 96.0%

- Continue to advocate for concept of medical home, provide support to existing providers, explore CMEs to community physicians, pediatric offices, health departments

▪ NPM 4 – Insurance: 96.8%

- Rate negotiations with MCOs and Medicaid
- Standards Action Learning Collaborative – AMCHP
- Attempt to educate to assure adequacy of insurance
- Continuation participation with state health benefit exchange as Certified Application Counselors

▪ NPM 5 – Community Based Services: 96.2%

- Further autism expansion to improve timely access to services – including
 - Parent Summit
 - Possible participation in LEND grant application
 - Ensure cultural diversity in autism screening
 - Continue to build infrastructure, allow partners to take over direct services where possible
- Telehealth expansion possibilities into other disciplines
- First Steps point of entry services

▪ NPM 6 – Transitions: 68.8%

- Ensure conformity with Got Transition and AAP guidelines/best practices
- Continue to stress transition, including development of transitions content for hemophilia and sickle-cell patients at the University of Louisville
- Develop evidence-based or evidence-informed measures

▪ NPM 12 – Early hearing screening: Data TBA (last year: 98.5%)

- Presentation(s) for pediatric residents
- Quality improvement initiatives
- Increasing knowledge base of physicians and medical homes
- Building effective referral pathways
- Continued participation of reorganized EHDI advisory
- Aim to reduce loss to follow up from 18% to less than 15% by age 3 months
- Use of Audiology scorecards

▪ SPM 7 – Healthy weight: 36.5%

- Focus on how to collect data with an ever-changing population
- Does agency process positively, negatively (or neither) affect outcomes in any way?
- Consider data of long-term patients
- Continue to collaborate with coalitions locally and statewide

▪ SPM 8 – Transitions Action Plan: 92.3%

- Continue to expand on efforts as part of agency's 5-year plan
- Implement transitions piece for hemophilia and sickle cell patients through University of Louisville
- Develop evidence-based and –informed measures

State Action Plan and Strategies

- **Transitions**
 - Plan to be developed and submitted by 7/15/16
- **Insurance**
 - Plan to be developed and submitted by 7/15/16
- **Easy Access to Services and Resources**
 - (1) Access to Medical and Specialty Care
 - Based on available data and, in conjunction, with SPM #Y, study feasibility of expansion of eligibility criteria to new disciplines to ensure more CYSHCN needing specialty care receive it
 - Assess underserved areas such as asthma, diabetes
 - Expand eligibility and/or formalize processes for existing programs such as muscular dystrophy (pilot), cerebral palsy
 - Continue to roll out clinics for Autism Spectrum Disorder (ASD), including new disciplines for CSHCN, including psychiatry
 - Continue teleneurology and expand service to other disciplines
 - Decrease wait time by improving CSHCN clinic flow
 - Targeted outreach to educate communities and providers about services provided through CSHCN, as per communication plan
 - Ensure insurance coverage as per strategies identified in NPM #15, such as serving as “kynectors” and premium assistance programs
 - (2) Availability of Provider Networks
 - Funding of University of Louisville neurology resident
 - Partnership with Health First Bluegrass to assure medical home service availability
 - UK partnerships
 - Provision of OAE screening equipment and training in First Steps early intervention points of entry
 - Studying feasibility of potential CSHCN recruitment initiatives
 - CSHCN participation in KHIE
 - In-service training to provide quality ASD services
 - Studying feasibility of establishing regional ASD assessment centers within CSHCN offices
 - (3) Development and Promotion of an Easy to Access System of Supports and Resources
 - Partnering with DCBS to offer Foster Care Support programs to assure services for medically fragile youth in foster care as well as population in or at risk of placement outside the home
 - Developing and implementing a transitions component to the Hemophilia Treatment Center program, in addition to other transitions efforts in conjunction with NPM (#)
 - Developing metrics as per SPM (#) to measure the perception of easy of use among both CSHCN-enrolled and non-enrolled CYSHCN
 - Expanding the Una Mano Amiga program outside of the pilot area
 - Office of Autism partnership working to connect and develop community services, including the convening of parent summits
 - Continuing partnership with the Advisory Council on Autism Spectrum disorders, which provides a central location for the collection, dissemination and coordination of information regarding services and supports for Kentucky citizens on the Autism Spectrum, and promotes greater collaboration among both private and public service providers
 - Reducing “loss to follow-up” by referring those at risk to qualified audiology assessment centers
 - EHDI initiative with Early Start and Head Start
 - Implementing guidance received as a result of ALC and activities toward implementing provisions of refined and revised CSHCN Standards of Practice

- Administering F2F program to assist with navigation of services
- Care coordination and enabling services such as social work, therapies, etc.
- Use of social media to alert families of CYSHCN to services, events, resources, etc.
- First Steps point of entry for Early Intervention Services with hopes to expand access across the state

▪ **Increase Data Capacity**

- Re-engineering, in substance and format, the internal data collection system (i.e. clinic comment card surveys) used to capture information to inform regarding services provided, needs expressed, quality improvement desired, and progress made toward performance measures
- Developing a plan to review untapped data resources to identify trends in the incidence of specific conditions (including those on the current CSHCN eligibility list and others queried) among Kentucky children
 - Medicaid claims data
 - Hospital discharge data
 - Kentucky Birth Surveillance Registry (KBSR) data
- Continuing to develop efforts to analyze other available data sources, including the revised National Survey of Children's Health (including both publicly available statewide data and restricted county-level data) and information available through sources such as the Kentucky Department of Education
- Convening an advisory committee on CYSHCN data (including those CYSHCN not enrolled in CSHCN services) charged with assuring capacity development and addressing gaps (including those pertaining to diverse populations), including through requesting guidance, training, and technical assistance from sister agencies and others with expertise
 - Potential resources/partners may include:
 - Kentucky Department for Public Health epidemiology staff
 - Kentucky Office of Health Policy
 - MCHB Graduate Student in Epidemiology Program (GSEP)
 - University of Kentucky College of Public Health
 - Data Resource Center for Child and Adolescent Health
 - Kentucky State Data Center at University of Louisville

For more information regarding CSHCN, please visit our website at <http://chfs/ky.gov/ccshcn>, or



Find us on Facebook at

<http://www.facebook.com/pages/KY-Commission-for-Children-with-Special-Health-Care-Needs/100331209094>

